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ABSTRACT

Policy planners can create improved systems of care and new support systems for rural families who are raising children with disabling conditions or special health care needs, by recognizing the unique needs of these families, the ecology of local service delivery systems, and the special resource requirements of rural areas. Lack of information is a serious impediment to attaining the goal of providing family-centered, community-based, coordinated care in rural areas. Other factors to consider in planning services include: health status profiles differ from those of urban communities; rural communities have different concerns, needs, and resources; demands on professionals may be overwhelming; significant economic problems exist; there is a lack of adequate transportation; access to services is restricted; and the lack of population density results in a paucity of health care services. Implications for policy and planning include: (1) localizing service planning and delivery; (2) increasing and enhancing the family role in child care; (3) developing interagency networks; and (4) coordinating cross-government private resources. (Contains 13 references.) (JDD)

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RURAL ISSUES IN PLANNING SERVICES FOR YOUNG CHILDREN WITH SPECIAL NEEDS

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Creating options for rural families who are raising children with disabling conditions and have special health care needs poses a great challenge to policy planners. Twenty-nine percent of children in the United States reside in rural or frontier areas. One million of these children face living with a disability. Planners can create improved systems of care and new possibilities that will support these children and their families in their quest for needed services if they recognize the unique needs of these families, the ecology of local service delivery systems, and the special resource requirements of rural areas.

Despite a growing interest in rural health care issues and a growing body of information about the general issues that affect health care in rural areas, there is little known about services or funding for services for young children with special health care needs. In the Office of Technology Assessment's extensive, new document, Health Care in Rural America (United States Congress, 1990), issues related to children with chronic illnesses and disabling conditions occupy only a few paragraphs. The limited data in other literature do not identify the types of services available, how they are organized, and what can work in rural areas to serve this population.

This lack of information is a serious impediment to attaining the goal of providing family-centered, community-based, coordinated care in rural areas for young children with special health care needs and their families (Patton, 1989). Planners and administrators need information about what does and does not work, how other states and communities have solved problems, and how such care can be financed. Researchers need information to begin formulating questions about the efficacy of various programs, the needs of rural communities, and the impact on families. Finally, those coordinating training programs for professionals must have information about the skills that those professionals will need to be successful in rural areas and information about the ways in which training can further the goal of family-centered, community-based, coordinated care in rural America (DeLeon, Wakefield, Schultz, Williams, & Vanden Bos, 1989).

An important further consideration in planning services is that health status profiles of rural communities differ from those of urban communities. In general, people living in rural areas have a greater incidence of chronic and disabling conditions as well as serious injuries (Norton & McManus, 1987; Baker, O'Neill, & Karpt, 1984). Infant mortality is also higher in rural areas, due in part to lack of access to prenatal care, lack of high risk perinatal care, and general economic and social problems in rural areas (United States Congress, 1990).

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The Ecology of Rural Life

When considering issues related to policy and planning for rural communities, it is helpful to understand how rural communities are identified. Most studies of rural areas use one of two government designations to define a rural area. The first is that used by the Office of Management and Budget. A non-metropolitan area is defined as a living area outside a Metropolitan Statistical Area (MSA). An MSA is defined as a county that includes either a city of 50,000 or more people, or an urbanized area of at least 50,000 people that is part of a county or counties with at least 100,000 people. In 1988, about 23% of the population of the United States lived in non-metropolitan counties (U.S. Department of Commerce, 1989a; Cordes, 1989). About 21 million children lived in such areas, making up approximately 33% of the non-metro population (McManus & Newacheck, 1989).

A second definition of rural is the Bureau of the Census designation of "non-urban," which includes communities of fewer than 2,500 people. Approximately 28% of the population of the nation live in such areas (U.S. Department of Commerce, 1989b). A further designation of rural areas has also been made to acknowledge those areas of low population density, particularly in the western part of the country. Frontier areas have been designated as those with fewer than six people per square mile (United States Congress, 1990).

When planning health (and other) services for young children with special needs in these rural areas, there are some salient features to keep in mind. All rural communities are unique and, therefore, have different concerns, needs, and resources. Existing communication and power structures, often informal in nature, can be key to planning and delivering services. Self-determination often pervades planning efforts; community members usually prefer to be in charge of creating services in their area. Services to children with special needs are closely linked to community attitudes. Key persons representing power sources (whether he/she be the judge, the school board chairman, or the local farmer) have considerable influence over resources for families. Understanding the linkage patterns that have been established with services outside the community represents an important aspect of the planning process.

For families caring for children in rural areas, there are some issues that may influence their needs and use of services. Some rural families will receive rich resources from extended family members and neighbors; others are isolated from family and can rely only upon immediate family members for assistance. The care of children with special health care needs may present a tremendous challenge to these families. Multiple services may require multiple appointments and special home treatments, and intense family involvement may be necessary for a treatment program to succeed. Many families spend considerable time and energy commuting to services, often driving up to 100 miles twice a week to see a health care professional. Often rural families are directly tied to the economy of the area; when the economy declines, so do their resources. Valuing their independence, they may resent dependency on public resources. Some rural families view professionals as outsiders, especially if the

professionals have not lived a long time within the community. These families may have difficulty accepting professionals' recommendations. Distinct cultural-group values attached to illness and disability can further influence the way some rural families relate to services.

Professionals from over 40 subspecialty areas (e.g., family practice, pediatrics, nursing, social work, psychology, physical therapy, occupational therapy) work in rural settings. They are a diverse group with multiple backgrounds and interests. Some have been specially trained to work with rural populations, some reside within the rural area, and some were raised in the rural area–and all of this affects their relationships with families. These professionals all have different abilities to invest in the community, adapt to change, withstand hardship, and create new resources. They have different expectations based on education, knowledge of laws, connections with other services, and past experience with families from diverse cultures. Retaining these professionals is often difficult. Some have years of training and are seasoned professionals, thereby finding the isolation of the rural setting attractive and non-stressful. Others are novices who miss the support of mentors and the stimulation of a broader professional and personal community. The professional demands may be overwhelming. Professionals often have a responsibility to work with families from birth to death, requiring extensive expertise; children with special needs may represent only a small portion of the population they serve. In addition, salaries in rural settings are often less competitive than they are in urban settings, making recruitment and retention even more difficult (Palsha & Bailey, 1990).

Many rural agencies are part of greater systems within the states and receive their mandates from these sources; data are often managed at higher levels. Isolation can interfere with agency administrators' receiving complete information about laws and state policies. The cost of delivering specialized services can be high in rural areas because of fewer professional resources, low incidence conditions, transportation barriers, and other rural conditions. Funding problems are paramount for most public and non-profit agencies. Support from local citizens' groups often significantly impacts budgets and agency capacity.

Challenges to Providing Services in Rural Communities to Young Children with Special Needs and their Families

In rural areas, the problems of providing family-centered, community-based, coordinated care for young children with chronic illness and disabling conditions are set against the background of significant issues affecting the total system of rural-area health care. Not surprisingly in rural areas, the most frequently reported problems encountered in serving children with special health care needs mirror the general problems facing rural health care systems. Problems with economics, transportation, availability of services, funding of care, and availability of personnel top the list (Bronheim, Fire, Nolte, Magrab, & Ingraham, 1992).

Economics of the Rural Community

One in six rural families lives in poverty, which means that about 26% of children in rural areas live below the poverty level. In the South, where 25 million of the 57 million rural residents of the country live, the issue of poverty is even more intense. Four out of ten people in the South are poor, elderly, or both (Rowland & Lyons, 1989; U.S. Department of Commerce, 1989). This economic issue has an impact on health care for young children in a number of ways.

First of all, the effects of poverty are often so overwhelming that health-focused programs alone cannot seem to have an impact on reducing health-related problems (United States Congress, 1990). Second, poverty limits access to health care, and thus may contribute to an increase in chronic and/or disabling conditions. For example, 30% of non-metro, poor children have not seen a physician in more than one year (McManus & Newacheck, 1989). Third, poverty affects the insurability of patients, and thus has an impact on access to care and the viability of health care programs. Rural areas have low incidences of persons with health insurance. Since many rural workers have low-wage, low-benefit jobs, they have less access to private coverage, but are also ineligible for public coverage. Many of these workers are self-employed or are in "seasonal" work. As a result, 12% of children in rural areas are uninsured and another 16% are insured only part of the year. Medicaid coverage is also more difficult to get in many rural states (McManus & Newacheck, 1989; Rowland & Lyons, 1989; Cordes, 1985).

Transportation

A major problem affecting health care in rural areas is lack of adequate transportation. This includes lack of public transportation, poor or no roads, extremely long distances to services, and lack of economic means for personal transportation. This difficulty is especially acute in frontier areas (United States Congress, 1990).

In a study of 106 rural health programs serving young children with special needs, 34% cited transportation as a major problem (Bronheim, et al., 1992). These difficulties were noted even though two-thirds of the programs had geographic limitations on the area they served and 41% served only one county. These problems included the drain that transportation costs puts on budgets, the lack of roads and/or equipment to get patients to services or services to patients, the enormous distances between families and needed services, and the lack of communication technology that could save physical travel. In some areas, weather conditions and geography intensified these difficulties.

Although rural areas have, at times, pioneered the concept of home-based services as a solution to these transportation issues, in a recent study of rural health programs for children, 15.3% of the programs listed "lack of home-based services" as one of their top three concerns (Bronheim, et. al, 1992). The problems that plague other types of care in rural areas–transportation and

financial issues–seem to be at the root of difficulties with the development of home services in some communities.

Issues Affecting Accessibility of Services

The question of whether care is available and accessible to all young children in rural areas with special health care needs must be addressed. While programs may exist to serve the needs of this population, access to these services may not be straightforward. Frequently programs are restricted in terms of whom they can serve. There may be financial restrictions, ethnic restrictions, age restrictions and diagnosis related restrictions. In order to receive services from restricted programs, clients may have to meet certain criteria.

In a recent study of rural health services for children with special health care needs, four areas of criteria for participation in programs were examined: geographic criteria, income criteria, race/ethnic origin criteria, and condition (medical, behavioral, social, at-risk) criteria (Bronheim, et. al, 1992). With respect to geographic location as a determining factor in the eligibility for receipt of service, two-thirds of the programs surveyed limit access based on geographic location. Geographic boundaries for inclusion for participation in programs were as follows: community/county (41%), regional or multi-county (38.4%), statewide (15.7%) and multi-state (1.0%). Income or financial criteria for participation in the program were required by nearly a third of the programs. Conversely, 70.2% of these programs had no financial/income criteria for their clients in order to receive services. Of those programs having an income requirement for program inclusion, 19% served families with income at or below poverty level, while an additional 38.7% served families with income up to 200% of poverty. Of the 462 programs responding to the survey, only six programs (representing 1.3% of the sample) required clients to meet an ethnic or racial criterion for receipt of services: multiple ethnic/minority groups served (n=2); Native American (n=1); Alaska Native or Native American (n=2); other, not specified (n=1). Of the programs responding to the survey, over half (58.7%, n=270) had diagnosis or condition as a requirement for receipt of program services. Examples of some common diagnostic criteria were: developmental problems (28.3%), at-risk (17.3%), specific condition (13.2%), and administrative discretion (19.5%).

Inadequacy of Services

Because of the economics, the lack of population density to support professionals and institutions, and other factors of rural life, there is a paucity of health care services in rural America. As rural areas continue to lose population, they encounter greater difficulties in supporting services needed by young children with chronic illnesses and disabilities. Hospitals are closing for lack of patients and adequate payment. As rural areas become less populous and poorer, their existing hospitals face a financial crises, because they cannot shift costs to private and paying patients (United States Congress, 1990; Rowland & Lyons, 1989).

Providing and maintaining professional services is also a problem in rural areas. Although the overall number of physicians in the nation has been increasing, the shortage in rural areas continues. There are fewer than half as many physicians for the same population levels in rural areas as there are in urban areas (91 versus 216 physicians per 100,000 people). The rural area physicians tend to be general or family practitioners rather than specialists or sub-specialists. This adversely affects children because there are relatively few pediatricians in rural areas as compared to urban areas (United States Congress, 1990). Children under 15 vary dramatically in their use of a pediatrician versus a family or general practitioner, depending upon what type of community in which they live. Approximately 61% of urban children received their medical care from pediatricians, compared with only 33% of children in non-metro areas (McManus & Newacheck, 1989). While this difference may have little significance for children who are relatively healthy, it can have significant impact on the care of young children with highly specialized and/or technical health care needs. Services of allied health professionals such as occupational and physical therapists, nutritionists, and speech pathologists are also in short supply in rural America (U.S. Department of Health and Human Services, 1990). This shortage dramatically affects the ability to implement early intervention services.

Because the population of many rural areas is spread out, and because families may not be aware of either a child's special needs or the availability of services for those needs, identification of children with special needs is a problem in rural communities. An especially significant finding in a recent survey of rural health programs for children with special health care needs (Bronheim, et al., 1992) indicated that 15% of the respondents found Child Find services to be problematic. Medical referrals to diagnostic and specialty services, especially from the newborn nursery, also were a problem. The survey found that almost six percent (5.7%) of the respondents reported lack of specialty health services at the local level. As one respondent noted, "In that area you will find only one pediatrician, so many families travel from one to five hours on difficult roads to see a pediatrician. In our region (9 counties) there is no pediatric neurologist, so families need to travel across the state to that individual."

Implications for Policy and Planning

Localizing Service Planning and Delivery

Solving the dilemmas associated with providing services in rural areas can include those strategies affecting service delivery, system design, program accessibility, and program resources. Local-level planning is a critical element, because planning must be based upon needs of families and familiarity with local resources. Local representatives should be involved in state level planning to assure communication and understanding of rural needs. Additionally, local planners must have access to statewide data from various agencies to assist them in developing programs and identifying needs and resources.

The challenge is to provide families with the services they need as close to home as possible. Locating services in proximity to families, however, is not an easy task in many rural areas. Vendors must be encouraged to establish satellite operations utilizing mobile clinics or community clinics. Where this is not possible, transportation solutions must be found, or creative technology utilized, to provide a broad range of care including assessments, treatments, and training programs.

Increasing and Enhancing the Family Role in Child Care

Making services family-focused is crucial in rural areas. A "high touch" approach usually works very well. This type of approach is a manner of relating to families and children in a positive way. Ways to support the family's role in the child's care may include: helping families plan, considering the family members as part of the assessment team, teaching parents to teach the child, advocating for the family-physician relationship, providing guidance and assistance to families in using the services offered by the agency, and teaching parents to be "co-case managers."

Interagency Networking

In rural areas, care coordination is a key to enabling families and service systems to interrelate more effectively. Care coordination strategies should provide knowledge to enable families to utilize available resources, including: making appropriate referrals, scheduling of appointments, arranging for services, and decreasing red tape for clients. Agencies can utilize interdisciplinary care management teams or employ full time case managers to accomplish this. For young children with special needs, coordination between tertiary centers and local systems is a priority. The tertiary center must provide information back to the referring physician and other professionals in the local community. Appointments and travel are important elements to coordinate for families. Admitting and discharge care conferences with local agencies, held by the tertiary center, if necessary by telephone, can be very effective in coordinating care. Regular contact between the tertiary center and local services must be promoted.

Interagency efforts bind systems together and have an opportunity to enhance rural service delivery systems. Interagency networks represent an important solution to providing adequate services in rural areas for young children with special needs and may incorporate interagency administration, interagency services, and interagency funding. These networks can address scheduling regular meetings of community providers to update one another on services available, establishing early intervention councils, developing one-on-one contact with other agencies, and employing technology related networking. Actual interagency activities can involve interagency agreements, Child Find implementation, co-location of services and staff, contracting for services, performing interagency team assessments, and engaging in shared case management.

The problems facing young children in rural areas with special health care needs mirror those of all individuals seeking health care in rural areas.

Solutions that have been achieved for other special populations, such as the elderly, may be of benefit. Developing shared programs may be appropriate. The challenges to families where services are both scarce and distant are enormous.

Coordinating Cross-Government Private Resources

Obtaining needed resources for rural programs for young children with special needs involves gaining public commitment, expanding fiscal resources, and recruiting and retaining personnel. Public commitment strategies enable a broad base of community representatives to identify resources. Forming local coalitions in rural areas to "put community back into community" and fostering advocacy roles for families further strengthen public support in rural areas. When professionals reside in the community they serve, they foster credibility and create linkages. Longevity of programs themselves engenders public support. Public commitment is strengthened when programs address a clear community need.

In considering the crucial issue of accessibility to services for young children with special needs, Child Find represents a key resource. The effectiveness of Child Find in rural communities must be maximized. Child Find activities should go beyond the resources of one agency by using informal mechanisms of public awareness such as service directories, and by setting a wide target population. Child Find activities should be conducted regularly on a community-wide or interagency basis with participation of all agencies working with the target population.

Informal mechanisms should be encouraged to create adequate public awareness. Local providers should keep agencies informed through personal contacts; trusted members of the community can be made aware of services and notices can be placed in informal gathering places. Of course, the more formal mechanisms of the media (print, radio, and television) should also be utilized.

With respect to effective fiscal strategies, successful programs for young children with special needs in rural areas receive resources from public funding, third-party funding, private contributions, and/or contractual arrangements. Programs can and should receive resources from multiple state and federal resources; at times services that are covered through Medicaid waivers are very beneficial. To be able to seek the varied resources required for survival, rural agencies must stay constantly apprised of new public resources and changes in existing resources. Information is vital to these agencies, but often very difficult to access.

Non-public, third-party resources are also helpful, especially when coverage can be obtained for case management, occupational therapy, and physical therapy. Private contributions, such as "in kind" or actual payment, donated space, or direct service dollars for clients, are of particular assistance in rural areas.

Using contractual arrangements is an especially effective technique in rural areas where human resources are scarce. Contracted therapists, purchased programs like respite care, and paid private sector physicians for 24-hour coverage can fill the gaps and help provide comprehensive service delivery to young children with special needs.

Building an adequate and qualified staff is a goal for many rural programs. Training incentives and opportunities are essential to offer state-of-the-art services in rural areas. Personnel shortages can be addressed by expanding the roles of existing personnel. Enhancing the skills of existing personnel can be an effective solution to providing more appropriate services to families with young children. For example, nurses might be trained to case-find, provide parent support, find resources, make referrals, and coordinate services.

Developing adequate and appropriate services for young children in rural areas with special needs will require cooperation and understanding at all levels of government (the public sector). It will also require cooperation and understanding at all levels of the private sector. It is the responsibility of our entire American society to assure equitable solutions for all of our citizens–including those families with young children with special needs–living in rural areas. Policies at a federal and state level must be informed by local experiences. It is critical that we build stronger links among all governmental and private entities.

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